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On behalf of the Scleroderma Foundation
Testimony March 13, 2008 before the Labor, Health and Human Services and Education
Subcommittee of Appropriations

Chairman Obey and members of the Subcommittee, thank you for the opportunity to appear before you today. And I especially want to thank Congresswoman Roybal-Allard and Congresswoman Linda Sanchez who are both from Southern California.

I am Cynthia Cervantes, I am 13 years old and in the eighth grade. I live in Huntington Park in Southern California. Two years ago I was diagnosed with scleroderma.

I must confess I am more nervous being here today in front of you all than when I was told I have Scleroderma. However, for your information, as I was told, Scleroderma means literally “hard skin”. What it does, especially in my case, it causes my internal organs to harden and become smaller.

Two years ago I began to experience sudden weaknesses, my body would ache and my vision was blurry, some days it was so bad I could barely get myself out of bed and go to school. I was taken to see a doctor after my feet became so swollen that calcium began to ooze out. It took the doctors one year to figure out exactly what was wrong with me, because of how rare Scleroderma is and how complicated the symptoms are.

Once again, I have been told that there is no known cause for Scleroderma, which affects three times as many women as men. Generally, women are diagnosed between the ages of 25 and 45, but some kids, like me, are affected earlier in life. There is no cure for Scleroderma, but there are treatments. Treatments that have been developed with the support of the NIH.

Today I have to take nine pills a day and use an inhaler three times a day and I always have to wear gloves and a sweater, even on a hot day, as a part of my treatment. Every month I also have to go to the doctors to get more shots and I have to eat a special diet because my scleroderma is making my internal organs contract, and sleep at an angle, because it helps me digest my food.

I love to play basketball, but it is very difficult now because I become tired very quickly and it is hard to keep up with the other kids.

The local Scleroderma Foundation’s Outreach Program has been very helpful to me and my family. The Foundation provided us with materials to educate my teachers and others about my disease.

Also, the local Southern California support groups the Foundation helps organize are very helpful because they help show me that I can live a normal, healthy life, and how to approach those who are curious about why I wear gloves, even in hot weather.

It really means a lot to me to be able to interact with other people in the same situation as me because it helps me feel less alone.

Mr. Chairman, because no one knows what causes scleroderma, and we have a great deal to learn about it in order to be able to effectively treat it, I respectfully ask you to please increase funding for the National Institutes of Health (NIH) so treatments can be found for other people like me who suffer from this sickness.

I would also ask that you make it known to the leaders of the NIH and the National Institute of Arthritis and Musculoskeletal and Skin Diseases, which is part of NIH, that you consider Scleroderma to be a priority and that more funds be allocated for clinical trials and to encourage more doctors and researchers to study it.

Mr. Chairman, on behalf of the thousands of people suffering from Scleroderma and the Scleroderma Foundation, I would like to thank you for this chance to speak before the Subcommittee and for your consideration of my request. Thank you.